

A Public Administrator Looks at Chronic Illness Surveys

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THE CURRENT popularity of chronic illness surveys at the county level invites scrutiny. Everyone seems to favor them, yet I have gained the impression that they are not creating revolutionary changes in community services. Their disturbingly vague effects led me to examine chronic illness surveys on the assumption that they are expected to stimulate a change in the way of doing things for the chronically ill.

My method of analysis was based on three principles.

1. Administration is the art of getting things done.
2. Paperwork is a product of administration.
3. Product analysis is a behavioral science research technique designed to provide insights into the behavior which produced the product.

The paperwork products from six county surveys fed from the community to the central files of the New York State Department of Health were reviewed against the normative standard of the administrator: Was anything accomplished?

Chronic illness surveys vary in scope. Some take a specialized approach, such as a survey of rehabilitation resources. Others try to look broadly at the complexities of modern society affecting the individual with chronic illness. However, all surveys revealed that the factfinding activity was expected to produce some change in the patterns of community service for

the chronically ill. Surveys look to a disturbance of the established order.

Government and Community Dualism

A public administrator recognizes that within our democratic state, organized on constitutional grounds, there exists a dualism which affects the organization of any form of community activity. This dualism places the community or society on one hand and the government or state on the other. In all six surveys, there was evidence of this dualism and its associated mythology. Without discussing this factor theoretically, I merely point out that, in every instance, the guiding committees handled the situation by involving both "government" and "community" organizations in planning the surveys. Interests were usually identified as representing one or the other group. Other dichotomies were used, but without the same consistency. Some represented a classification by skills, economic status, or institutional association.

Community Political Function

The technique used in solving the government-community dichotomy revealed to me that the surveys were conducted as community political functions. In our democratic society, political function consists of fostering a process of discussion which results in agreement on objectives and, we would hope, a propensity to reexamine them periodically. Governmental agencies are thereafter charged with or excluded from followup. One might characterize this as the process of attempting to resolve conflict-

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ing interest demands on the basis of power. However, community groups need to have their interest aroused because, initially, they are uninterested in the results of a chronic illness survey. So it is my thesis that it is not until the planning starts that the discussion of politics commences. Therefore, at the outset we are interested in attempting to identify from what point in the community interest in chronic illness surveys originates. We also want to know how the survey as a social phenomenon is perceived by the parent group, as well as its goals and results.

I will try to answer these questions.

- Who started the survey?
- What patterns of community involvement were developed to deal with the diverse interests?
- What were the goals?
- How were the facts collected?
- What recommendations came out of the survey?
- What actions resulted?

I will not identify the six counties where the surveys were conducted, since this paper is not based upon site visits. My answers to the questions are derived almost entirely from the written records accumulated in the central office—a paper-shuffler's insights developed by shuffling paper.

Who Starts Chronic Illness Surveys?

Apparently the survey starts without single-person parentage. I am sure that this is not the case. Insiders may know the initiator, but for the public, chronic illness surveys are started by agencies. Statewide agencies interested in public health and welfare, official agencies, and councils of social agencies appear as sponsors. I suspect the design of a chronic illness survey includes an attempt to create a picture of spontaneous upswelling of popular support. Anonymity of the individuals actually initiating surveys would then be necessary.

However, the informal correspondence does suggest that in almost every instance, the idea was conceived either by a particular individual with a professional interest to serve or by a citizen disturbed by the lack of coordination in planning community services to meet the needs

of the chronically ill and aged. If you accept this assumption, you may then conclude that initiators of chronic illness surveys are already convinced of the need for change and are seeking a mechanism for bringing it about. Expressed another way, chronic illness surveys are organized to pull groups into the early planning stage and stimulate the political process of discussion, thereby bringing about a change in a political equilibrium involving diverse interests.

Who Is Involved?

This brings us to the question, how were the diverse interests concerned with chronically ill and aged brought together in the various surveys? It was at this point that success or failure in bringing about a change was determined in the six surveys.

The outstanding failure resulted in a ½-inch pile of paper. The survey was initiated without adequate attention to the enumeration of the various interests concerned. Conceived by a single professional, described in appropriate euphemisms, carried out without real attempts to gain support of all necessary agencies, it failed to produce even serious discussion in the economic, industrial, and political sectors of the community. The clues to predict failure were in the prospectus. There was no action which changed patterns of services for the chronically ill and aged.

A second pattern of involvement which also failed had a good prospectus. But mistakes were made in selection of representatives. Conceived by a few professionals in community services, it failed to obtain planning committee membership which represented significant leadership of the diverse interests in the community. This was a "communitywide project involving the participation of professional health and welfare disciplines, civic groups, community and industrial organizations, and volunteer citizens," to quote the prospectus. However, representation, while balanced, was not significant. The critical level of power for decision making within each of these interest groups was not recognized. One observer stated that the committee was filled with citizens of considerable prominence as well as persons in the pro-

fessional field, but the political powers were ignored. Citizens high in the power structure, who were appointed "served only as window dressing and failed to take an active part in the survey."

Representation without significant commitment by the interest group led to failure of followthrough on recommendations; nothing was changed. Perhaps it was by design that representatives were selected who satisfied the community organizer's requirement of representation, but who were not in a position to commit their special interest groups to any final decision to act on the fruits of the survey.

Two surveys, as judged by the pragmatic standard of creating action afterwards, revealed a high degree of sophistication in handling the involvement of diverse interests. The other two surveys fell into the intermediate range, and performance and results were variable.

The records of the surveys producing changes showed that a great deal of time and effort was put into the first phase of organization. Spokesmen who wished to play a prominent role were appointed as chairmen. Committees were large but carefully organized into subcommittees dealing with specific areas of concern. Assignments were made with care. This attention was directed not only at the significant points of possible support but also at the significant points of possible opposition.

The preparation had depth too. For example, the orientation process was extended to secretaries of physicians who could have spelled success or failure for some phases of the data collection.

The successful surveys had anonymous initiators, balanced representation, representatives selected from the appropriate hierarchical level, and orientation in depth. The skill with which this political process was carried out, in my opinion, determined the success or failure as judged by subsequent action on the recommendations.

What Are the Goals?

Setting the stage for discussion extends to selection of goals. Apparently goal setting is not a critical factor. All surveys used general

statements. It was difficult to determine exactly what they meant, but it was also difficult to disagree with them. Perhaps starting the discussion calls for general statements which will not arouse immediate antagonism. Participants learn about the specific goals in the process of working on the committees.

One survey's stated goal was "to determine whether a demographic analysis of certain types of health services would be useful to community agencies," whatever that means.

Another survey identified its goals as the appraisal of existing facilities, the counting of people served by existing facilities for the disabled, and, by careful analysis of the needs, establishment of priorities and determination of intermediate or long-range steps in planning for the medical and nonmedical care of the long-term patient. Who knows what a priority is or how we arrive at it?

Slogans were also used to justify the need for surveys. One was "A Design for Decision." What the design was or who was to make the decision was not spelled out.

Nonspecificity of goal statement seems no handicap. It may be a necessary obfuscation.

Fact Collection

The fact-collecting phase revealed some divergence in approach. One survey was carried out by asking agencies providing services to fill in questionnaires about the kinds of people they were serving and requesting from them a statement of policy as to whether or not they wished to serve this sort of individual. In another one, factfinding consisted of an inventory of facilities involved in medical care, an appraisal of their policies, and a household survey of a sample of people to check them against established criteria for disability to obtain some index to the extent and nature of chronic illnesses in the area.

Another survey specifically rejected the idea of doing a communitywide house-to-house survey, and confined itself to a limited sample of the caseloads of facilities serving the chronically ill. The technique was directed at defining the patterns of service as they might affect a class of patients. The involvement feature was merged with the factfinding process in that

recommendations for improvement of the service were part of the survey effort. It was expected that by combining involvement and survey effort and making recommendations as data were collected, an immediate impact on service to the chronically ill would take place.

However, the skill and completeness with which facts were discovered were good in all surveys. I infer that factfinding technique was not a critical factor.

The facts the surveys revealed were monotonous. Review of the findings showed that most localities had the same problems with minor variations. The home-grown data could have been predicted with sufficient precision for administrative purposes by merely extrapolating from national survey results. The impact of the facts, after they were assembled, seemed to be of no significance. Community surveys which relied upon dissemination of facts produced no changes. Communities did not alter their behavior when only facts were presented.

What Were the Recommendations?

The recommendations derived from the facts were fairly concrete, but they were also monotonously similar: home care services, more rehabilitation centers, improved recordkeeping, and in some instances, another survey. My interest brightened when I ran across one recommendation which was not clear cut, particularly since it was the product of a good survey. The general recommendation was that home nursing services should be improved. This particular community was blessed with two overlapping nursing services; the recommendation did not provide for a specific method to eliminate the overlap but opted for continued negotiation of the issues. This suggested that an impasse had developed in terms of the survey's capacity to mediate divergent viewpoints on the best community organization for nursing service. I suspect this situation is still in a state of flux and will probably remain so for some time.

Action After the Survey

It is difficult to analyze these data and to make value judgments on the final results of the

chronic illness survey technique in these communities. Not all were started at the same time, followup information is variable, and there was no attempt to measure changed attitudes in the community. A change in attitudes, or stated another way, in political climate, may be the most significant result because it causes disturbances in the equilibrium. The correspondence following the survey did show an increased realization by community agencies that there was a need for coordinated and continuing effort to deal with their problem.

Among the concrete actions, the most common outcome was the organization of increased nursing services in the home. Almost every survey recognized the need for this increase, although there was considerable variation in carrying it out. Apparently this step upsets the fewest people and is the easiest to accomplish. Another common recommended action was the development of mechanisms for improved recordkeeping and evaluation by teamwork of patients' needs. Here again the clearinghouse concept on information is old and familiar, and no one objects to dressing it up in new clothes.

In three instances it was recommended that a county health district be organized in the area. The only consequent actions were the organization of committees in two counties to discuss the matter. No county health districts were organized. This sort of change in the equilibrium is not taken lightly. But people are willing to talk about it.

Summary

An area contemplating a chronic illness survey should not be deluded by the expectation that the mere collection of facts is going to influence subsequent behavior in the community. Even with the best groundwork, it should not be expected that a revolution will follow. And it should be kept in mind that the critical point is at the organization phase. I am convinced that an evaluator reading the prospectus and the list of committee appointments can predict success or failure with a high degree of precision before the first interview or examination of an institution or its policies has started.